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TITLE: An Investigation of the Facilitative and Inhibitory
Variables Impacting Breast Health Practices in Low-
Socioeconomic Status Black Women of African-American and
Caribbean Descent

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FOREWORD

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X For the protection of human subjects, the investigator(s) adhered to policies of applicable Federal Law 45 CFR 46.

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N/A In the conduct of research involving hazardous organisms, the investigator(s) adhered to the CDC-NIH Guide for Biosafety in Microbiological and Biomedical Laboratories.

Introduction

Black women of low-socioeconomic status (SES) demonstrate a high incidence of breast cancer mortality associated with late-stage diagnosis. Breast cancer screening, including mammography, breast self-examination, and clinical breast examination, remains the most effective route to early cancer detection. Studies indicate poor adherence to breast cancer screening regimens among low-income minority women. An overall objective of the study is the construction of models that can explain screening practices in low-SES black women. This will be accomplished in two separate waves. In the first wave, facilitators and barriers to breast cancer screening participation among low-SES women of African-American and Caribbean descent will be determined through qualitative interview. This approach intends to provide a voice for the concerns and experiences guiding these women in their screening choices. The current study incorporates an approach –avoidance theoretical framework that considers preventive screening behaviors to be both desirable and aversive. Based on the factors provided by the respondents in the first wave of the study, culturally-sensitive Q-Sort instrumentation will be designed that will allow participants to rank order these factors as facilitators or barriers and therefore, provide a powerful approach to testing the theoretical paradigm. Finally, innovative modeling techniques will be applied to determine the strength of models that explain breast health care practices among low-SES Black women, either as idiopathic to the general population of low-SES Black women or specific to African-American or Caribbean cultural groups.

Report Body

Research accomplishments are presented in a temporal sequence segmented into semesters to provide a description of the evolution of research tasks and the context in which they occurred. Embedded in this sequential structure is a discussion of research accomplishments that fall into four general categories: accomplishments of a formative nature, accomplishments related to pre-doctoral training, accomplishments specific to the approved Statement of Work, and problems associated with completion of tasks specific to the approved Statement of Work.

Semester 1: Fall 1999

Infrastructure Issues

Coinciding with the beginning of this grant, two site-related issues impacted getting the study underway. First, it was the expectation of the Dental School at UMDNJ that my study would be embedded in a larger population-based study proposed by Dr. Theresa J. Jordan. It was this mother grant that provided my access to necessary staff, a research space that would be available to me for the remainder of the study, and the full cooperation of school and department heads. When this grant was not funded, there was no longer any person contractually involved at the site as all support and approval documented in the letters included in my grant proposal were directly related to Dr. Jordan's intended study. Efforts to reestablish infrastructure would need to begin from the very beginning.

At the same time, the Dental School experienced major turnovers in top leadership positions. A great deal of time this semester had to be spent in repeated meetings with top-level people whose familiarity with and approval for the study was required. Major turnovers in

leadership positions prevented efforts to reestablish the infrastructure necessary for beginning the study.

Also as stated in the approved Statement of Work, Internal Review Board clearance was required from both New York University and UMDNJ. The NYU IRB was submitted in October 1999 and conditionally approved in December. The Internal Review Board at New York University granted permission to carry out human subject research conditional on the approval from the Human Subjects Board at UMDNJ. Staff turnover, coupled with the lack of infrastructure at the project site prevented submission of the UMDNJ IRB. Approval and support to carry out the study at the Dental School was required at the clinic-staff level before it could be sought at the Human Subjects Committee level. With site issues at a standstill, attention was turned to other necessary tasks.

Literature Review

The research literature pertinent to the topic of study was updated from several sources. Since the literature compiled thus far related to the initial grant submission in June 1998, updated research studies and government documents needed to be searched for, acquired and reviewed. **Appendix A** lists the updated documents and literature reviewed during the entire course of the present study. While begun in the Fall 1999, this literature update has been an ongoing task throughout the time of this grant.

Data Issues

After being assigned a research space at NYU, I spent three weeks setting up and organizing the space. Tasks included the creation of an extensive filing system, final design and reproduction of all data collection instruments, and setting up a computer with all appropriate software.

Finally, using the Statistical Package for the Social Sciences (SPSS) version 10.0, a dataset and accompanying data dictionary was compiled. Both files represent all demographic and instrument data to be collected for the study. The present study requires a large amount of data-related organization and management. Extensive demographic information as well as variables from four different measurement instruments needed to be identified. In addition, computed variables representing total scores or weighted information were designed. Information regarding measurement level, category labels and missing values became part of the extensive working data dictionary. **Appendix B** contains a copy of the working data dictionary.

In summary, most of the tasks attended to are formative in nature with the exception of completion of required IRB proposals. The approved Statement of Work states that IRB approval would be obtained during this period. Approval was granted by NYU, but the IRB proposal for UMDNJ was completed and not yet submitted at this time due to the issues relating to infrastructure and site personnel discussed above.

Semester 2: Spring 2000

Site Visits

Work began during this semester to reestablish site infrastructure. Multiple visits to UMDNJ under the supervision of my on-site supervisor, Richard L. Montgomery, D.D.S.,

M.P.H. began in Fall 1999 with the goal of understanding the physical layout, systems and procedures of the Dental Clinic, appointment scheduling and patient access to facilitate eventual participant solicitation and data collection. The Dental School serves socially disadvantaged individuals who live in the urban community located in and around Newark, New Jersey. A large portion of those utilizing clinic services are poor and lack health insurance. In addition, they demonstrate a low utilization of preventive health screening. Most previous research on breast cancer screening adherence has targeted women breast health care facilities. Thus, women already engaging to some degree in breast health care are being asked to speak for those women who are not. This site allows an investigation of women not likely present in the breast health care system.

a. Physical Plant

The UMDNJ-New Jersey Dental School is large and complex facility housed within the sprawling Medical Center campus. The Dental School has nine clinics located on two levels off a spacious, glass-domed lobby, which forms the central waiting area. In addition to the clinic space, there are research laboratories, seminar rooms and lecture halls all designed for both teaching and dental health care delivery. Clinics for Oral Diagnosis and Radiology, Oral Surgery, Periodontics, Endodontics, Orthodontics and Pediatric Dentistry are located on the main floor. General and Hospital Dentistry and Fixed and Removable Prosthodontics are housed on the upper level. Research laboratories, consulting areas, a central sterilization facility and faculty offices are located on these two levels, adjacent to the main treatment areas. Additional rooms serving as temporary office space available to faculty and staff are located on both levels. Those patients not receiving emergency or surgical services will be solicited for participation in the study. Thus, I will be soliciting participants from the Oral Diagnosis, Periodontics, Orthodontics

and General Dentistry clinics. Contact with support staff in each of these clinics as well as instruction on how to work within the schedules and procedures of each of these clinics was facilitated through my multiple site visits. In addition, an empty room right off the central waiting area has been identified and provided for use in data collection.

b. Typical patient load and treatment procedures

Approximately 80 percent of the new patients who are registered are accepted by screening faculty, are assigned to a student, accept a treatment plan and enter into dental treatment. A review of the data collected in the clinic's registry database for 1997 listed 2817 women seen at least once in the clinic. Of these, 1324 were 40 years of age or older and 45 percent of the women were black. The clinic, thus, provides access to a substantial population of low-income Black women who are within the age groups targeted for screening.

Prospective patients typically coming into the clinic are assigned to a dental student under the supervision of faculty. Patient screening is the first step in a multi-step process preceding treatment implementation. Medical assessment of the patient takes place in the Oral Diagnosis and Radiology clinic. During the second visit to the General and Hospital Dentistry Clinic, the clinical treatment plan is discussed with the patient. Treatment does not typically begin until their third visit to the clinic. Treatment appointments are usually scheduled during one of two daily teaching blocks, at 12:00 p.m. and 4 p.m. Participants will be solicited at three times during the day; before and after the first block and prior to the second block.

When patients arrive, they register with a treatment receptionist and then move to the central waiting area. The wait is typically long and patients are told to set aside two to three hours per clinic visit. There is nothing to do during this long waiting period, which provides the researcher an opportunity to engage those waiting in the study. Since at any time, patients may

be waiting to register, to be seen for consultation or treatment or waiting to be discharged from various clinics, constant communication between the researcher and the clinic is required so that patients available to the study can be identified. Cooperation and guidance from these various clinic staff in patient availability and access has been assured during the many clinic visits made by myself this semester.

c. Access to Additional Medical School Resources

Working with Dr. Richard Montgomery, I made contact with the medical school-computing center and library facility to ensure my access to both resources. After explaining the purpose and scope of my research in the Dental School, I was granted full access to the computing center and limited access to the library. I will be able to use the computer center's wide variety of state of the art statistical, database, presentation and printing services during regular clinic hours. I will have access to all library material onsite only.

d. IRB Protocols

Internal Review Board procedures and protocols in a medical environment differ greatly from those in academic settings. The researcher consulted specifically with on-site persons for advice on putting together the IRB proposal within the dictates of Medical School requirements. The IRB proposal was completed, but it was decided not to submit the material until final approval was received from the appropriate top-level people at the Dental School to come into the clinic and carry out the study. It was the opinion of both myself and the on-site supervisor that clinic-level clearance by top-level staff should precede Human Subject Department clearance.

In summary, these multiple site visits have informed my understanding of Internal Review Board procedures and protocols, the clinic layout and scheduling procedures as well as facilitating communication between myself and those support staff that will be assisting me in access to potential study participants. In addition, I have been cleared to use important computer and library resources.

Staff Training

With the many tasks required of the study including qualitative data collection and transcription, quantitative data collection, entry and analysis, and ongoing literature updating, the need for research assistants became apparent. The search for potential research assistants began in February. Due to the non-paid nature of these positions, undergraduate assistants who were interested in the research process but not highly skilled were sought. As such, extensive training was provided after the two assistants were identified.

I made initial contact with the faculty person in charge of research method coursework and field placement in the College of Arts and Sciences at New York University. After two meetings, three students were presented for consideration. After interviewing these students one student was chosen to do her fieldwork experience on the present grant. I made another visit to Audrey Cohen College and after speaking with a colleague, an additional student who was also required to complete field placement was identified. Both assistants were new to the research process. For over a month, these assistants were trained in the following:

- a) How to use research databases, including PsychLit, Sociofile and Medline, to conduct ongoing searches for study-related literature.
- b) How to summarize collected research articles using the project's Research Review Summary Sheet

- c) How to create study-related databases with Microsoft Access
- d) How to do basic data entry into SPSS v.10.0

Databases necessary to organize the study were created in Microsoft Access between March and May. These databases archived the following information:

- a) All research articles that had abstracts on file in the research space
- b) All articles retrieved and summarized
- c) An ongoing list of articles to be retrieved and summarized
- d) A bibliography of all government working papers and other documents acquired off related Internet sites

Instrument Development

The largest undertaking for the Spring 2000 was the initial development of an instrument to measure access to and utilization of health care among the study population. The rationale behind this decision emerged from engagement in the ongoing process of literature review. During this process, critical studies were identified, alerting me to dimensions to be targeted in this instrument. This pre-doctoral study is motivated and informed by the discrepancy in breast cancer mortality and levels of screening practices between low-income minorities and other middle, and upper class populations. Several current government initiatives, including the Department of Health and Human Services ongoing initiatives Healthy People 2000 and Healthy People 2010, the DHHS Division of Health Promotion and Disease Prevention's Final Report on "Leading Health Indicators for Healthy People 2010 (1999), and the Institute of Medicine's report entitled "Access to Health Care" (1999) indicate that much of these discrepancies in health prevention behavior and health outcomes can be traced to the discrepancies in health care access

experiences by these underserved populations. Access is being defined as both the utilization and quality of health care as reported by health care consumers (Millman, 1993). The World Health Organization, in an ongoing initiative entitled "Health Systems: Improving Performance (1999,2000) has determined that any agenda to improve health systems for underserved populations must address the issues of *goodness* and *fairness*. Goodness is defined as "the best attainable average level of" of good health (pg. xi). Fairness is defined as "a health system that responds well to everyone, without discrimination" (pg. xi).

The "Leading Health Indicators for Healthy People 2010 Report" (1999) has included access to quality health care in their set of Life Course Determinants and Prevention indicators. The report applies two conceptual frameworks important to the current study. In the field model (Evans and Staddart, 1992) determinants of health, such as access to health care, are predictive of positive health behaviors such as cancer screening and positive health outcomes at the individual and population levels. The life course health development model (Halfron, Sutherland, & Inkelas, 1999) reflects evidence that "health outcomes and health status follow a developmental process in which current health status and outcomes are the product of cumulative inputs across the life span" (pg. 8). According to this model, health determinants such as health care access influence an individual's subsequent life course of preventive behaviors and health outcomes. The current study was designed to tap the factors influencing breast cancer screening that are based on the experiences and concerns of the women in question, and not on variables predetermined by the researcher. It appears, though, that attention to issues of health care access are necessary to provide a full representation of the experiences of these women in a health system that continues to present barriers to quality access and healthy outcomes. Low levels of screening participation and elevated levels of breast cancer mortality in the study population

speak directly to these health care barriers. As such, development of such an instrument began in earnest in early January 2000. Initial efforts were focused on evaluating current literature and government papers on the topic of health care access, both broadly, and as it applies to the study population. Refer to **Appendix A** for a complete list of references. The purpose of this inquiry was to establish those areas of utilization, quality of care, and health outcomes that would inform the initial item pool. Guidance was also provided by Dr. Richard Montgomery, the on-site grant supervisor, whose specialties include survey research in health care and service delivery to underserved urban populations, during two visits to UMDNJ. Subsequent item development began in March. The full instrument is discussed later in the report and referenced in an Appendix at that time.

Pre-doctoral Training

The principal investigator undertook a pre-doctoral training piece independently during this semester. As part of the current study, Q-methods will be employed. Using initial qualitative interviews to compile a list of factors influencing breast cancer screening participation, a culturally sensitive Q-Sort instrument will be developed by the researcher to determine the nature of these facilitators and barriers. A high-level understanding of the methodological and statistical aspects of Q-methods was desired. The questions of interest included:

- a) How can Q-methods be applied to test the strength of the theoretical approach-avoidance paradigm as it applies to breast cancer screening?
- b) How do Q-techniques differ from R-techniques?
- c) What are the historical and philosophical foundations of Q-methodology?

- d) What are the differing approaches to the design of Q-Sorts and the analysis of Q-Sort data, including the benefits and disadvantages of forced vs. free sorting?
- e) How can the psychometric rigor of Q-Sorts be evaluated?

Training was facilitated through collection and review of both current literature and classic works in the field of Q-methodology, ongoing participation in Q-method discussion forums on the World Wide Web, and membership in the International Society for Scientific Study of Subjective (ISSSS) to ensure access to archival documents and the Journal of Objective Subjectivity. See **Appendix C** for a complete reference list.

In summary, during Semester 2 of the study (Spring 2000), substantial movement was made in rebuilding infrastructure at the site so that data collection could begin. Again, most of the accomplishments of this semester were formative in nature, including the initial development of health care access instrument, the training of research assistants, the creation of study-related databases, and an important pre-doctoral training piece.

Summer 2000

By the middle of May, contacts with all necessary top-level people at UMDNJ had been completed. The principal investigator was familiar with the surroundings of the Dental School, its policies and procedures and their impact on efforts to acquire subjects and collect data. By the end of May a major problem for the study developed. As someone living with diabetes mellitus, I was taken gravely ill and hospitalized on May 29. Due to an infection of unknown origin, diabetic ketoacidosis set in resulting in severe dehydration, unmanageable potassium levels and

retinal and kidney impairment. Due to the substantial impact on several body systems, recuperation took place over the next two months.

Semester 3: Fall 2000

Resuming work, I was close to total recovery by the beginning of September and returned to school. My absence of several months led to returning to a project that was not yet in place and running. This fact coupled with the need to prepare a first Annual Summary Report by mid-October, led to my decision to contact my DOD Contract Specialist with great concern. The problems encountered in infrastructure rebuilding and due to illness were communicated to the Contract Specialist. It was determined that the deadline for the Annual Summary Report would be extended until mid-January of 2001. In the meantime, efforts to access the site in addition to several formative tasks would continue.

Issues Related to IRB Proposal

A revised IRB was completed in November to reflect changes in the scope of the study. This IRB packet was submitted to Dr. Richard Montgomery for review before submission to the committee. Problems with IRB approval at UMDNJ surfaced in December, when it was announced that the Internal Review Board was embarking on a review and revision of Human Subject policy and procedures. There was a moratorium in place on submission, which is presently being lifted.

Issues Related to Site Infrastructure

All meetings necessary to finalizing issues of infrastructure have taken place. Contacts have been made with top-level individuals, including the appropriate Department Chair and Dean, who have verbally consented to my carrying out the study at the Dental School conditional to IRB approval. This is a positive outcome considering the lack of contractual involvement of any person on staff at the Dental School. The principal investigator has met with all support staff who will be available in my efforts to solicit participants and collect data. A small workspace has been made available to the principal investigator where study-related tasks including data collection can take place.

Instrumentation

Work continued this semester on the development of the Access to Health Care instrument. See **Appendix D** for a copy of this and all study instruments. All items are now designed for the current version of the measure. Future piloting of the instrument may necessitate revisions. Based on a framework employed by Agency for Health Care Research and Quality (AHRQ) in the psychometric testing of their Consumer Assessment of Health Plans System (CHAPS), cognitive testing of the instrument was undertaken in November through the voluntary participation of medical professionals who are colleagues of the principal investigator. Cognitive testing provides assessment through feedback from interviews with medical professionals who are asked to react to the survey questions. According to Forsyth and Lesser (1991), cognitive testing is an effective technique for surveys in the early stages of development. The think-aloud method was employed, in which individuals were asked to verbalize their

thoughts on the individual items as they read and answered each instrument item out loud. Entire questions, words or phrases, and response choices that were ambiguous were identified. In addition, respondents were asked to suggest aspects of health care access not tapped in the instrument. As a result, six additional items tapping adherence to physician recommendations for prescribed medication and lifestyle changes were added. Finally, applying the CHAPS framework, it was decided that explicit reference points, such as “currently” or “at the present time” be incorporated into survey items to “standardize the amount of time about which respondents are asked” (AHRQ, 1997).

Pre-Doctoral Training

An additional pre-doctoral training piece was independently undertaken this semester. Qualitative interviews are being conducted for the first wave of data collection. Prior to this training effort, the principal investigator had limited knowledge of qualitative methods. Training took place in a formal doctoral-level qualitative methods course supplemented by immersion in qualitative literature, texts and Web-based documents. See **Appendix E** for qualitative methods references.

Training issues included:

- a) An overview of various qualitative methods and techniques.
- b) How is a qualitative interview protocol designed?
- c) How are qualitative interviews coded and analyzed?

It has been decided that a very loosely structured interview protocol will be utilized. In an effort to conduct an interview that allows the participant’s voice (the emic voice) to emerge, the content of most follow-up questions will be driven by the participant’s narrative. Using the work

of Padgett (1998) and Morse (1994), decisions regarding data analysis have been finalized. Each interview will be recorded and transcribed. Through several readings, each interview will undergo line-by-line coding, where meaning units will be identified. Meaning units of interest are those pieces of information provided by the participants that describe factors that inhibit or facilitate screening participation. These meaning units will form the basis for items for the Q-Sort measure.

The analysis scheme will utilize "open coding" (Emerson, Fretz, & Shaw, 1995) where the emphasis rests on making sense of participants' experiences with screening as opposed to imposing preexisting or a priori concepts to their narratives. Constant comparative analysis (Padgett, 1998) will be the applied coding method. This method utilizes an iterative approach that begins with inductive meaning making, moves to deductive meaning making and then returns to an inductive approach. Meaning units emerge from the initial coding (inductive). Then one goes back over the data to ensure that it has been coded in a way compatible with these units (deductive). In this way, new codes often emerge (inductive).

To ensure the reliability of coded data, inter-rater consistency will be assessed by calculating a coefficient of correspondence (Cohen, Swerdlik, & Phillips, 1996) between the coding decisions of the principal investigator and a research assistant.

In summary, all work on infrastructure was completed during this semester. Delays in IRB approval have continued as a result of the reworking presently going on in that office at UMDNJ. It is anticipated that the IRB will need one final revision to reflect expected changes in Human Subject procedures and protocol. It is also anticipated that the new IRB system will be in effect shortly at which time the final IRB proposal will promptly be submitted for review. Development of the Access to Health Care Survey has moved very far along. All items have

been constructed. Cognitive testing of the instrument addressed problems with item clarity and construct validity. A second pre-doctoral training piece on Qualitative Methodology was completed. Decisions on design, data collection and data analysis were finalized.

Semester 4: Spring 2001

With the moratorium on IRB proposal submission presently being lifted, it is anticipated that my IRB package will be acted on at the first meeting to take place on March 1, 2001. The IRB package is ready and awaiting submission. Formative work on the study has continued. All study-related databases have been updated during this semester. As part of the ongoing update of research literature, work has been ongoing since January 1 to gather and review up-to-date documents and reports from a wide variety of government agencies. Government resources include: the World Health Organization, Department of Health and Human Services, Institute of Medicine, The Cancer Institute, The National Women's Health Information Center, The Health Information Center for Minority Women, The Office of Minority Health Research, The Agency for Health Care Research and Quality, the CDC's Morbidity and Mortality Weekly Report, The National Health Information Center, and Healthy People 2000 and 2010 initiatives. Documents relating to breast cancer screening, disparities in minority health outcomes, and disparities in minority access to health care have been retrieved and summarized. **Refer to Appendix A for a list of document references.**

Key Research Accomplishments

- Completed and submitted IRB proposal to New York University and received approval conditional on project site approval.
- Completed IRB proposal for submission to UMDNJ-New Jersey Dental School Human Subject Committee (See Report Body for discussion of problems encountered with submission).
- Reestablished infrastructure at project site, UMDNJ-New Jersey Dental School, which became necessary since initial support was embedded in a mother grant that was ultimately not funded. This task included receiving support and clearance to carry out study from top-level staff at the Dental School, becoming familiar with the physical plant of the school and its multiple clinics and workstations, gaining an understanding of the schedules, procedures and protocols of the school, securing work space for data collection and other project-related tasks.
- As an ongoing effort, updated research literature and government document and reports applicable to the study goals have been retrieved and summarized.
- Design and ongoing update of dataset and data dictionary using the Statistical Package for the Social Sciences (SPSS) version 10.0
- Provided comprehensive training in research methods and protocols to two undergraduate research assistants.
- Created all project-related databases using Microsoft Access 2000.
- Development of Access to Health Care Instrument to measure utilization and quality of health care among the study population.

- As a first step to testing the psychometric rigor of the Access to Health Care Instrument, cognitive testing of the instrument was carried out and necessary revisions to the instrument were made.
- Completed pre-doctoral training piece designed to provide a deep understanding of the methodological and statistical aspects of Q-Methods.
- Completed additional pre-doctoral training piece designed to provide a deep understanding of methodological issues involved in interview protocols and procedures, interview coding, analysis and interpretation and data reliability.

Reportable Outcomes

- Development of instrument to assess Access to Health Care.
- Psychometric testing of instrument to assess Access to Health Care.

Conclusions

While substantial site-related problems occurred that influenced the timetable of this research endeavor, much formative movement has been made over the last year. Problems emerged when the mother grant of Dr. Theresa J. Jordan (the pre-doctoral grant supervising mentor) was not funded and expected support for the study was removed. As result, the on-site infrastructure needed to rebuilt from scratch. This was a huge undertaking that required much time and effort on the part of the principal investigator. Impeding this effort was the major turnover in top-level staff at the Dental School during a substantial part of the first year of this grant. Also impacted were efforts to receive IRB approval from the Dental School. When infrastructure was finally in place and the IRB proposal package could be submitted, the Dental School placed a moratorium on all IRB submissions as an overhaul of Human Subjects procedures and protocols for the entire Medical School was implemented. Currently, the moratorium has been lifted and it is anticipated that my IRB package will be acted on at the first meeting to take place on March 1, 2001.

Despite the impact of the above problems on meeting Statement of Work deadlines, many tasks of a formative nature have been addressed and completed. Several important pre-doctoral training pieces were undertaken to increase my knowledge and skill level in two methodological areas significant to the research study, qualitative methods and Q-Methods. The extensive training in research methods and techniques for two undergraduate research assistants was necessitated by the inability to contractually support research staff. As an ongoing effort, all pertinent research literature and government reports have been updated and reviewed. Emerging from this effort, critical studies and government initiatives were identified that provided evidence of the need to broaden the scope of measurement in the study to address access to health care

among the study population. An instrument to measure the utilization and quality of health care experienced by low-income Black women was designed and cognitively tested.

So What

Incorporating Access to Health Care Instrumentation

With a significant proportion of the Dental School patient population lacking health insurance, the quality of and access to health care becomes of vital importance for the present study.

Current government initiatives provide evidence that discrepancies in health prevention behavior and health outcomes among poor minority individuals can be traced to the discrepancies in their health care access experiences. Issues of goodness (attaining the best average level of good health) and fairness (a health system that responds well to everyone without discrimination), as conceptualized by the World Health Organization, are currently viewed as essential to any agenda to improve health outcomes and health systems for underserved populations. Measuring access to health care among the study population and examining its intersection with breast cancer screening practices will inform the knowledge base on cancer screening among underserved populations. With much of the current initiatives on health care focused on collecting quantitative data on service usage, attempts to measure the perceptions about quality of health care while identifying problems associated with health care access will imbed issues of breast cancer screening into the proper health system context.

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Annual Summary Report

Appendices

Appendix A: Updated Research Literature and Government Reports

Topic: Breast Cancer Screening Among Minority Women

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Appendix B: Excerpt from Data Dictionary

| | | | |
|-----------------------------|----------|------------------|---|
| Subject Code | 1 | Code_id | Label information |
| Length | 8 | | |
| Variable Label | None | | |
| Missing Values | None | | |
| Measure | Scale | | |
| Date of Interview | 2 | date_int | |
| Length | XX/XX/XX | | |
| Variable Label | None | | |
| Missing Values | 99 | | |
| Respondent Source | 3 | source | |
| Length | 8 | | |
| Variable Label | 1 | | Current patient (presently receiving trtment) |
| | 2 | | Screening patient (not receiving trtment) |
| | 3 | | Emergency patient |
| Measure | Nominal | | |
| Date of Birth | 4 | Birthdat | |
| Length | XX/XX/XX | | |
| Variable Label | None | | |
| Missing Values | 99 | | |
| Place of Birth | 5 | birthplce | |
| Length | 8 | | |
| Variable Label | TO BE | | CODED |
| Measure | Nominal | | |
| Current Residence | 6 | curr_res | |
| Length | 8 | | |
| Variable Label | TO BE | | CODED |
| Measure | Nominal | | |
| How long lived there | 7 | longlive | |
| Length | 8 | | |

| | | | |
|---|----|---|--|
| Variable Label Measure | | None Scale | |
| Caribbean Is. Length Variable Label Measure | 9 | carib_is 8 TO BE Nominal | |
| ESL Length Variable Label Measure | 10 | esl 11 1 2 Nominal | No Yes |
| Other Language Length Variable Label Measure | 11 | lang 8 TO BE Nominal | |
| Language spoken Length Variable Label Measure | 12 | langspk 8 1 2 3 4 5 Nominal | English Spanish French (all variations) Creole Other |
| Language write Length Variable Label Measure | 13 | langwrit 8 1 2 3 4 5 Nominal | English Spanish French (all variations) Creole Other |
| Language read Length Variable Label | 14 | langread 8 1 | English |

| | | | |
|---------------------------|----|----------|-------------------------|
| | | 2 | Spanish |
| | | 3 | French (all variations) |
| | | 4 | Creole |
| | | 5 | Other |
| Measure | | Nominal | |
| <u>News source</u> | 15 | news | |
| Length | | 8 | |
| Variable Label | | | TO BE CODED |
| Measure | | Nominal | |
| Community Info | 16 | commserv | |
| Length | | 8 | |
| Variable Label | | | TO BE CODED |
| Measure | | Nominal | |
| Community Service | 17 | commserv | |
| Source | | | |
| Length | | 8 | |
| Variable Label | | | TO BE CODED |
| Measure | | Nominal | |
| Med'l Serv. Source | 18 | medlserv | |
| Length | | 8 | |
| Variable Label | | | TO BE CODED |
| Measure | | Nominal | |
| Marital Status | 19 | marital | |
| Length | | 8 | |
| Variable Label | | 1 | Single (Never Married) |
| | | 2 | Married/Partner |
| | | 3 | Separated |
| | | 4 | Divorced |
| | | 5 | Widowed |
| Measure | | Nominal | |
| No. of children | 20 | Kids | |
| Length | | 8 | |
| Variable Labels | | None | |
| Measure | | Scale | |

| | | | |
|----------------------------|-------|-------------------|--|
| No. of births | 21 | Births | |
| Length | 8 | | |
| Variable Labels | None | | |
| Measure | Scale | | |
| Religion | 22 | religion | |
| Length | 8 | | |
| Variable Label | 1 | Roman Catholic | |
| | 2 | Southern Baptist | |
| | 3 | Jehovah Witness | |
| Nominal | | REST TO BE CODED | |
| Strong Relig. Faith | 23 | Religbel | |
| Length | 8 | | |
| Variable Label | 0 | No Opinion | |
| | 1 | Strongly Disagree | |
| | 2 | Disagree | |
| | 3 | Agree | |
| Ordinal | 4 | Strongly Agree | |
| Spiritual Person | 24 | Spiritual | |
| Length | 8 | | |
| Variable Label | 0 | No Opinion | |
| | 1 | SD | |
| | 2 | D | |
| | 3 | A | |
| Ordinal | 4 | SA | |
| Present Occupation | 25 | Occup | |
| Length | 8 | | |
| Variable Label | | TO BE CODED | |
| Nominal | | | |
| Time in Occup | 26 | Timeocc | |
| Length | 8 | | |
| Variable Label | | NONE | |
| Interval | | | |

Appendix C: Q-Methods References

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Appendix D: All Instrumentation

I. DEMOGRAPHIC INFORMATION AND ACCESS TO HEALTH CARE SURVEY

Code ID: _____

Date: _____

Clinician ID: _____

Respondent Source

Currently being screened for dental treatment _____

Current dental clinic patient (receiving dental care) _____

Dental screening patient (treatment not yet begun) _____

Emergency dental patient _____

1. Date of Birth _____

2. Place of Birth _____

3. Where do you currently live? _____

4. How long have you lived there? _____

5. How long have you lived in the United States? _____

6. What is your ethnicity:

African-American _____

Caribbean (state which Island) _____

Other (specify) _____

7. Is English your Second Language (ESL) Yes _____ No _____

8. What other languages do you speak? _____

9. When you speak, what is your primary language? _____

10. When you write, what is your primary language? _____

11. When you read, what is your primary language? _____

12. What is your main source of news? _____

13. What are your main sources of information about your community? _____

14. What are your main sources of information about the services in your community?

15. How do you know where to go for medical services?

16. What is your marital status?

Single (never married) _____

Divorced _____

Married _____

Widowed _____

Separated _____

17. How many children do you have? _____

18. Number of births: _____

19. What is your Religious affiliation? _____

I will read you a statement. Please pick the choice you most agree with:

20. I consider myself to have a very strong religious faith:

Strongly agree _____

Agree _____

No opinion _____

Disagree _____

Strongly disagree _____

21. I am a very spiritual person:

Strongly agree _____

Agree _____

No opinion _____

Disagree _____

Strongly disagree _____

22. What is your present occupation? _____

23. How long have you done this work? _____

24. Indicate your highest level of education:

Grades 1-8 _____

Some College _____

Some High School _____

College Graduate _____

High School graduate _____

Graduate school _____

Technical or vocational school _____

25. What is the number of people living in your immediate household? _____

26. Now I am going to ask you who they are:

Spouse/partner _____
Children (how many) _____
Dependent children _____
Non-dependent children _____
Parents (how many) _____
Other (specify) _____

27. What is the total amount of your individual monthly wages, not including benefits (check off choice that applies):

\$0.00 - \$500.00 _____
\$501.00 - \$1,000.00 _____
\$1,001.00 - \$1,500.00 _____
\$1,501.00 - \$2,000.00 _____
\$2,001.00 - \$2,500.00 _____
\$2,501.00 - \$3,000.00 _____
More than \$3,000.00 _____

28. What is the total amount of your household monthly wages, not including benefits? (check off choice that applies)

\$0.00 - \$500.00 _____
\$501.00 - \$1,000.00 _____
\$1,001.00 - \$1,500.00 _____
\$1,501.00 - \$2,000.00 _____
\$2,001.00 - \$2,500.00 _____
\$2,501.00 - \$3,000.00 _____
\$3,001.00 - \$3,500.00 _____
\$3,501.00 - \$4,000.00 _____
More than \$4,000.00 _____

29. Do you receive any of the following benefits:

Retirement or pension benefits _____
Social Security Pension (SS) _____
Public assistance _____
SSI _____
Social Security Disability (SSD) _____
Veteran's Benefits _____
Unemployment Insurance _____
AFDC _____
Medicaid _____
Medicare _____
Any other benefits (specify) _____

30. Do you have health insurance at this time? Yes _____ No _____

(a) If yes, what kind _____
(b) If yes, who is the insured? _____

(c) If yes, how long in this plan _____

31. Think back over the last year about the different medical services you received. In the last year have you:

| | | |
|----------------------------|-----------|----------|
| Seen a doctor | Yes _____ | No _____ |
| Had a physical examination | Yes _____ | No _____ |
| Seen a gynecologist | Yes _____ | No _____ |
| Seen a dentist | Yes _____ | No _____ |
| Seen a nurse practitioner | Yes _____ | No _____ |
| Seen a healer | Yes _____ | No _____ |
| Seen a chiropractor | Yes _____ | No _____ |
| Seen an acupuncturist | Yes _____ | No _____ |
| Seen a homeopathic | Yes _____ | No _____ |
| Seen an herbalist | Yes _____ | No _____ |
| Seen a hypnotist | Yes _____ | No _____ |

32. Overall, how satisfied are you with the medical services you receive:

Very satisfied _____
Satisfied _____
Somewhat satisfied _____
No Opinion _____
Somewhat dissatisfied _____
Dissatisfied _____
Very dissatisfied _____

33. What is the biggest problem in getting a doctor's appointment?

(Possible prompts):

Contacting the medical office _____
Getting through to someone I can speak to _____
Getting an appointment that fits my schedule _____

34. What is the biggest problem in keeping a doctor's appointment?

(Possible prompts):

Sudden change in schedule _____
Getting to the medical office _____
Finding childcare _____

35. What is the biggest problem when attending the doctor's appointment?

(Possible prompts)

Waiting to be seen by the medical professional _____
Being sent to other doctors for additional evaluation _____
Filling out all the paperwork _____
Paying for the medical services _____

36. Do you have a chronic illness? Yes _____ No _____

37. What type of chronic illness do you have? (List all) _____

38. Do you take medication for your chronic illness at the present time? Yes _____ No _____

39. What kind of medications do you take for your chronic illness? (List all)

40. How satisfied are you with the medical care you get for chronic disease?

| | |
|-----------------------|-------|
| Very satisfied | _____ |
| Satisfied | _____ |
| Somewhat satisfied | _____ |
| No opinion | _____ |
| Somewhat dissatisfied | _____ |
| Dissatisfied | _____ |
| Very dissatisfied | _____ |

41. What are some factors that might keep you from using medical services when you need them? List any that apply.

42. What are some factors that encourage you to use medical services when you need them? List any that apply.

43. What do you like most about the medical care you receive?

44. What do you like least about the medical care you receive?

45. How did you get to your appointment today?

46. How do you usually get to your medical appointments?

47. Do you usually travel to medical appointments:

From your home _____

From your job _____

Other (specify) _____

48. Do you go to different locations for different medical services? Yes _____ No _____

49. Do you know if there is a health clinic within close distance to you? Yes _____ No _____

50. If yes, how often do you use the services there:

Most of the time _____

Some of the time _____

Rarely _____

Never _____

51. How would you rate your travel to and from medical appointments:

Very easy _____

Easy _____

Difficult _____

Very difficult _____

52. Do you have any limitations or handicaps that keep you from getting medical care when you need it? Yes _____ No _____ If yes, explain:

Please tell me how much you agree with the following statements:

53. I trust my health care providers to give me the proper medical care:

Strongly agree _____

Agree _____

No opinion _____

Disagree _____

Strongly disagree _____

54. I trust my health care providers when they make suggestions on how I can best take care of myself:

Strongly agree _____

Agree _____

No opinion _____

Disagree _____

Strongly disagree _____

55. I trust my health care providers when they prescribe medication for me:

Strongly agree _____

Agree _____

No opinion _____
Disagree _____
Strongly disagree _____

I would like you to fill in the blank:

56. I would feel better about my medical care if:

57. I would like you to fill in the blank:

I would feel better about my medical care if my health care provider would:

58. When my health care provider prescribes medication for me, I

(a) Closely follow their instructions:

Always _____ Usually _____ Sometimes _____ Never _____

(b) Fill my prescription:

Always _____ Usually _____ Sometimes _____ Never _____

(c) Take the entire prescription

Always _____ Usually _____ Sometimes _____ Never _____

(d) Trust that the medication will make me feel better:

Always _____ Usually _____ Sometimes _____ Never _____

(e) Worry that the medication will have side effects:

Always _____ Usually _____ Sometimes _____ Never _____

59. When my health care provider makes recommendations about how I can improve my health, I:

(a) Closely follow their instructions:

Always _____ Usually _____ Sometimes _____ Never _____

(b) Agree with their recommendations:

Always _____ Usually _____ Sometimes _____ Never _____

(c) Understand their recommendations:

Always _____ Usually _____ Sometimes _____ Never _____

(d) Trust their recommendations:

Always _____ Usually _____ Sometimes _____ Never _____

60. When I do not follow my health care providers' recommendations, it is usually because:

61. When I do follow my health care providers' recommendations, it is usually because: _____

62. In the last 12 months, how many times did you go to the emergency room for medical care:

None _____ Fill in number of times _____

63. In the last twelve months, not counting visits to the emergency room, how many times have you gone to a doctor's office or clinic:

List number of times _____

64. In the last twelve months, my health care plan caused delays in my health care:

Strongly agree _____

Agree _____

Not sure _____

Disagree _____

Strongly disagree _____

65. When I go to see a doctor they usually explain things to me in a way that I can understand:

Strongly agree _____

Agree _____

Not sure _____

Disagree _____

Strongly disagree _____

66. When I go to see a doctor they usually treat me with respect:

Strongly agree _____

Agree _____

Not sure _____

Disagree _____

Strongly disagree _____

67. When I go see a doctor they usually listen carefully to what I have to say:

Strongly agree _____

Agree _____

Not sure _____

Disagree _____

Strongly disagree _____

II. INTENT TO BREAST CANCER SCREEN

We are very interested in learning about your thoughts on breast cancer screening. Please respond to each statement honestly. There are no right or wrong answers. List your level of agreement with each statement using the following scale:

| 1 | 2 | 3 | 4 | 5 |
|------------------------------|-----------------|-------------------|--------------|---------------------------|
| Strongly Disagree | Disagree | No Opinion | Agree | Strongly Agree |

- 1) I plan on having a mammogram sometime next year. _____
- 2) I plan on performing breast self-examination sometime next year. _____
- 3) I plan on performing breast self-examination several times next year. _____
- 4) I haven't really thought about having a mammogram this coming year. _____
- 5) I plan on performing breast self-examination once a month. _____
- 6) I have no intention of scheduling a mammogram this coming year. _____
- 6) I haven't really thought about performing breast self-examination in the future. _____
- 7) I plan on having a breast examination done by a health care professional sometime
next year. _____
- 8) I have no intention of performing breast self-examination in the coming year. _____
- 9) I haven't really thought about scheduling a breast examination in the future. _____
- 10) I have no intention of scheduling a breast examination in the coming year. _____

III. SCREENING BELIEFS SCALE (Champion & Scott, 1997)

Please list your level of agreement with each statement using the following scale:

| | | | | |
|--------------------------|-----------------|-------------------|--------------|-----------------------|
| 1 | 2 | 3 | 4 | 5 |
| <i>Strongly Disagree</i> | <i>Disagree</i> | <i>No Opinion</i> | <i>Agree</i> | <i>Strongly Agree</i> |

Mammogram:

1) Having a mammography will help me find breast lumps early.

2) I am afraid to find out there is something wrong when I have a mammogram.

3) I cannot remember to schedule an appointment for a mammogram.

4) Having a mammogram will decrease my chances of dying from breast cancer.

5) Having a mammogram costs too much money.

6) People doing the mammogram are rude to women.

7) If I find a lump early through mammogram my treatment for breast cancer :
may not be as bad.

8) Having a mammogram would expose me to unnecessary radiation.

9) Having a mammogram would be too embarrassing.

10) Having a mammogram is the best way for me to find a very small breast lump.

11) I have other problems more important than getting a mammogram.

12) Having a mammogram would take too much time.

13) It is difficult to get transportation for a mammogram.

14) Having a mammogram would be painful.

15) I don't know how to go about scheduling a mammogram.

16) It is difficult to get childcare so I can get a mammogram.

17) I am afraid to have a mammogram because I don't understand what will be done.

Breast self-examination:

1) When I do breast self-exam I am doing something to take care of myself.

2) Breast self-exam is embarrassing to me.

3) I do not feel I can do breast examination correctly.

4) If I find a lump early through breast exam, my treatment for breast cancer may
not be as bad. _____

5) Breast self-exam is not necessary if I have a routine mammogram.

6) Breast self-exam takes too much time.

7) My breasts are too large for me to complete breast self-examination.

8) Completing breast self-exam each month may help me to find breast lumps early.

9) It is hard to remember to do breast self-exam.

10) Breast self-exam is not necessary if you have a breast exam done by a health care provider.

11) My breasts are too lumpy for me to complete breast examination.

12) Completing breast self exam each month may decrease my chances of dying from breast cancer.

13) Doing breast self-exam will make me worry about what is wrong with my breast.

14) I don't have enough privacy to do breast self-examination.

15) I have other problems more important than doing breast self-examination.

16) I know how to perform breast self-examination.

17) I am able to find a breast lump the size of a pea.

18) I can perform breast self-examination correctly.

19) I could find a breast lump by performing breast self-examination.

20) I am able to find a breast lump which is the size of a quarter.

21) I am able to find a breast lump which is the size of a dime.

22) I am sure of the steps to follow for doing breast self-examination.

23) I am able to tell something is wrong with my breasts when doing breast self-examination

24) I am able to tell something is wrong with my breasts by looking in the mirror.

25) I can use the correct part of my fingers when examining by breasts.

III. BREAST CANCER SCREENING PRACTICES

(Saint-Germain & Longman, 1993)

We are very interested in learning about your experiences with breast cancer screening. Please answer each question honestly. There are no right or wrong answers to these questions.

- 1) Have you ever had a mammogram? Yes _____ No _____
- 2) Have you had at least two mammograms? Yes _____ No _____
- 3) Have you had at least three mammograms? Yes _____ No _____
- 4) Have you had two mammograms in the past two years? Yes _____ No _____
- 5) Have you had three mammograms in the past three years? Yes _____ No _____
- 6) Have you ever had a breast examination by a health care provider? Yes _____ No _____
- 7) Have you had a breast examination in the last year? Yes _____ No _____
- 8) Have you ever done a breast self-examination? Yes _____ No _____
- 9) Did you perform a breast self-exam in the last year? Yes _____ No _____
- 10) On average, how many times per year do you perform breast self-examination.
Yes _____ No _____

Appendix F: References on Qualitative Methods

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